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TITLE: A Longitudinal Study of Emotional Distress and the Use of
Complementary and Alternative Medicine in Women with
Breast Cancer

PRINCIPAL INVESTIGATOR: Dianne M. Shumay
Gertraud Maskarinec, M.D., Ph.D.

CONTRACTING ORGANIZATION: University of Hawaii
Honolulu, Hawaii 96822

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Introduction

The purpose of this study is to examine the extent to which levels of depression and anxiety and coping at three-five months post-diagnosis are related to complementary and alternative medicine (CAM) use at initial assessment and follow-up at 9 and 15 months. This study will also identify the types of CAM sought after by women with higher levels of anxiety and depression. Additional aims of the study are to provide pilot data for further research in developing interventions (such as mood regulation skills, coping skills training or treatment information) to meet the emotional needs and healthcare expectations of breast cancer patients. This study is funded as a predoctoral training grant. The research study serves as Ms. Shumay's doctoral dissertation.

Body

Three broad categories of tasks were performed on the project in the past year, culminating in the passage of Ms. Shumay's dissertation proposal, passage through three IRBs for human subjects approval and the beginning of data collection. First an extensive literature review was conducted leading to two theoretical models upon which to design the study, set hypotheses and guide analysis of data (Figures 1 and 2 below).

Figure 1 depicts a model in which three categories of variables are expected to predict greater degree of CAM use among women with breast cancer. First greater emotional distress, defined as greater levels of depression and anxiety, will be related to more CAM use. Next, the coping response styles anxious preoccupation and fighting spirit are expected to have a positive effect on CAM use, while fatalism and helplessness/hopelessness would be expected to have a negative effect. And lastly, a number of socio-demographic and clinical variables are also expected to predict greater CAM use: younger age, higher income, higher education level, being married, Caucasian ethnicity and receiving chemotherapy.

Figure 2 depicts a more complex model in which the variable categories are shown to be inter-related. This model is based upon Kornblith's (1998) vulnerability model of psychosocial adaptation of cancer survivors with the addition of CAM use as an outcome as well as a mediating variable. In this model, breast cancer and treatment are seen as the precipitating events that ultimately lead to psychosocial adaptation and CAM use. Sociodemographic and coping responses are viewed as mediating variables in that they represent the presence or absence of resources that lead to better or worse adaptation. The longitudinal nature of this study allows us to explore hypothesized temporal relationships between the variables. First, emotional distress at T1 is expected to predict degree of CAM use at T2, in so much as patients would be expected to use CAM in response to depression or anxiety; while greater degree of CAM use at T1 is expected to predict less emotional distress at T2 due to the possible psychological benefits of using CAM.

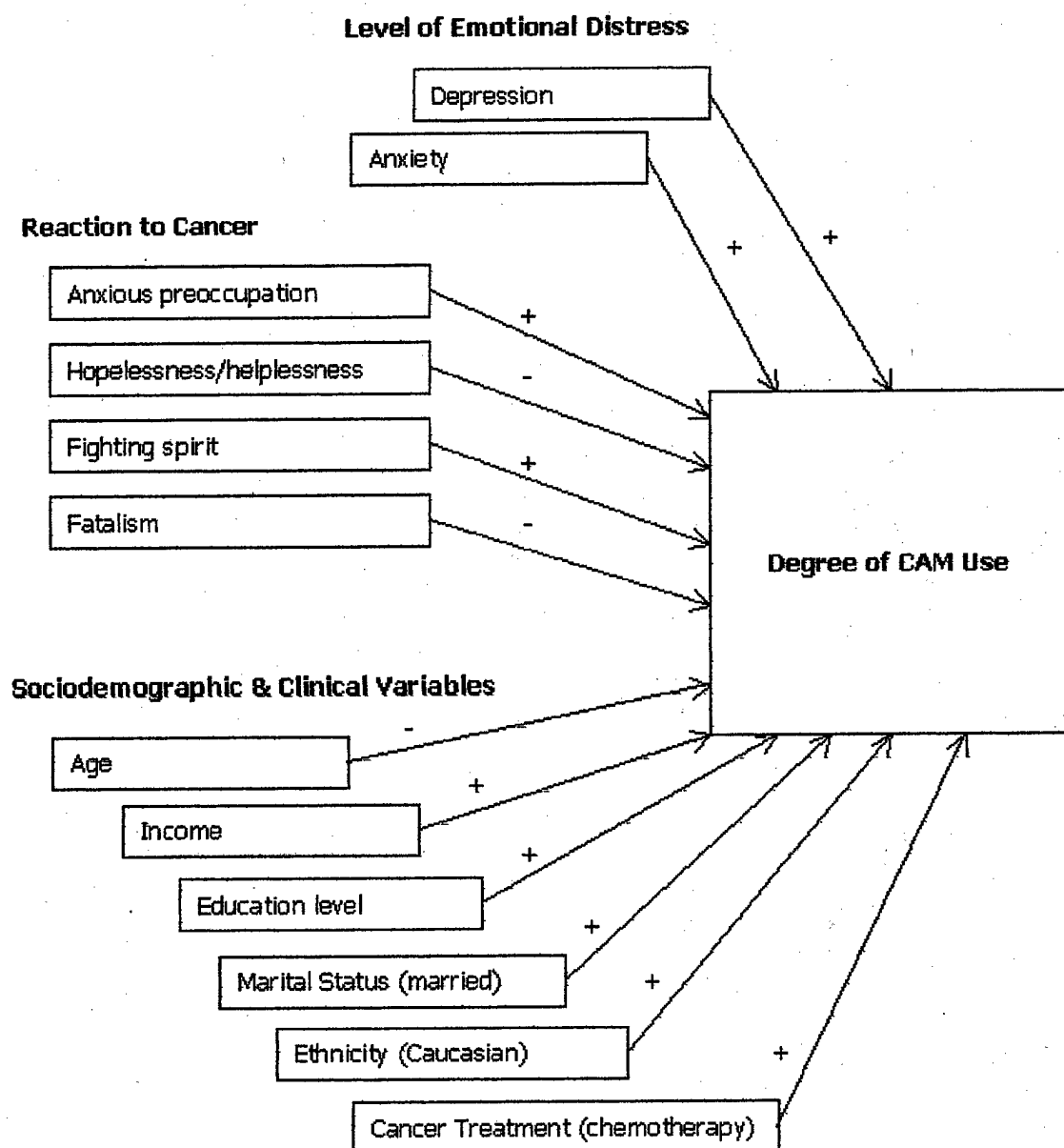


Figure 1. Hypothetical model of determinants of degree of CAM use by women with breast cancer.

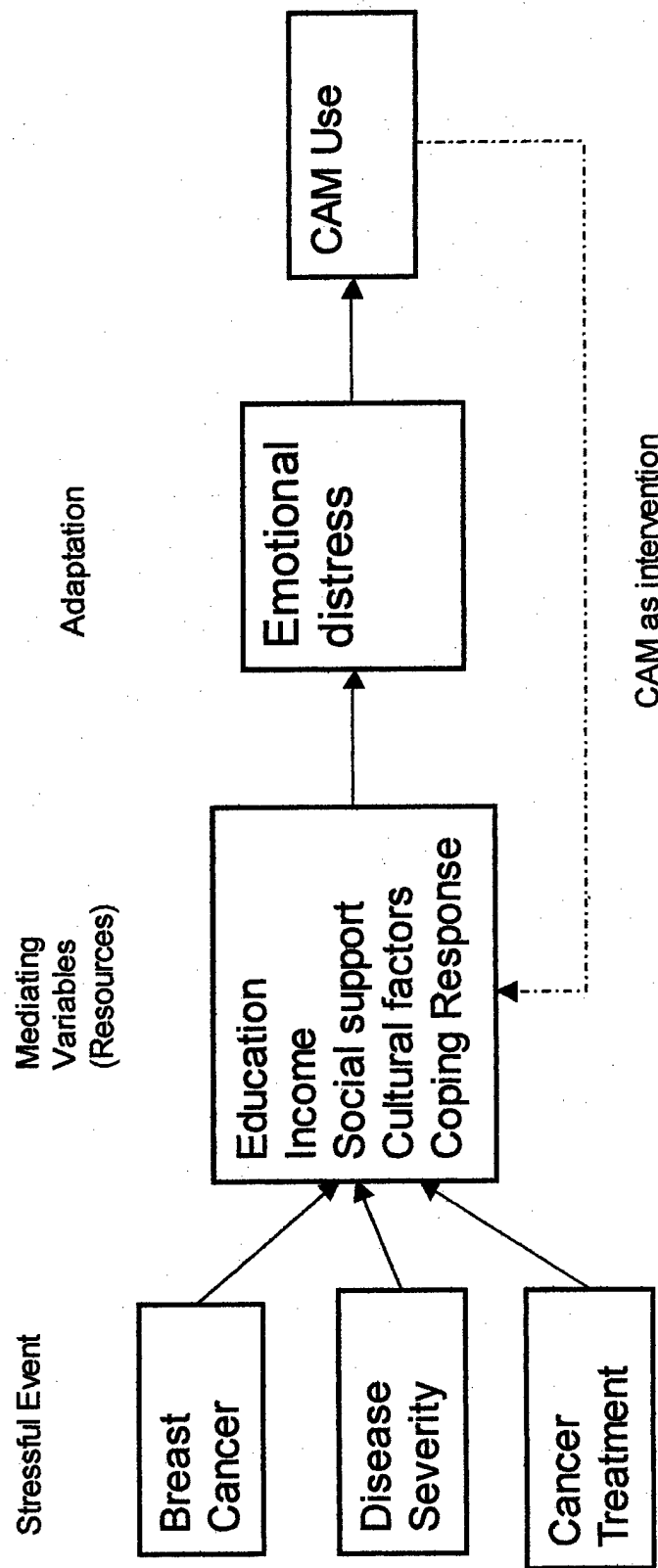


Figure 2. Vulnerability model of psychosocial adaptation with CAM utilization (Adapted from Kornblith, 1998)

A dissertation proposal was prepared based upon the literature review and proposed models (Appendix A). Dr. Maskarinec and Dr. Gotay at the Cancer Research Center and three other members of Ms. Shumay's dissertation committee assisted in guiding her dissertation preparation. In the process of preparing the proposal, Ms. Shumay also obtained and reviewed questionnaires, designed the demographic form and designed the CAM questionnaire. Her committee had input into the design of the new instruments as well as suggesting the addition of the Impact of Event Scale (IES; Horowitz, Wilner & Alvarez, 1979), an instrument designed to measure the stress of traumatic events. The questionnaire yields scores for the avoidance subscale and intrusive subscale.

Simultaneous with proposal preparation were applications to both the University of Hawaii Committee for Human Subjects and the DOD IRB. Because the dissertation committee had the final say in how the study was conducted and what specific questions could be asked, after the proposal was formally accepted, Ms. Shumay went back to both IRB's to report amendments to the protocol and obtained approval.

One of the most notable changes to the original protocol was the method for recruitment. Subsequent to the original grant proposal, the Hawaii Tumor Registry stopped their rapid case ascertainment system. Thus we could not access new breast cancer cases that way. Instead we had to contact oncology surgeons directly to request them to identify new patients for us to contact. We succeeded in getting the top six surgeons who do about 90% of Oahu's breast cancer surgeries to agree. Another change that was suggested by Ms. Shumay's doctoral committee was to extend the eligibility criteria for the first data collection point to up to five months post diagnosis to expand the number of eligible women.

We prepared materials for the study. We created cover letters and consent forms for mail surveys and we designed a recruitment brochure with a response card for women to contact us for participation. We also formatted the questionnaires for the computerized scanning system (Teleform). After we completed this task we pilot tested the questionnaires and revised the size and layout of some of the pages to ease readability. We also tested scanning the questionnaires to ensure that the data would be read correctly in the study database that we designed. We purchased supplies including envelopes, pens, labels, paper, cardstock and other miscellaneous supplies and duplicated questionnaires, consent forms, and prepared mailing packages. We contacted two hospitals to inquire about IRB requirements. One hospital (Kapiolani Medical Center) determined that our project was exempt. The other hospital (Kaiser-Permanente) reviewed our application and gave approval to access patients through their department of general surgery.

Subsequent to IRB approval and material preparation we began the subject recruitment and data collection phase of the project. As mentioned six surgeons agreed to distribute our study brochure to new breast cancer patients (<5 months since diagnosis). We personally delivered the brochures to the physician's front office personal, explained the study and are following up weekly to ensure that eligible women receive the brochure. Based upon this we have been able to recruit one woman for the study and collect her

completed questionnaire. Because we are targeting 125 women, we are now considering additional methods of subject recruitment, including going through the American Cancer Society; the Cancer Information Service; women's health fairs and breast cancer support groups. We are also considering asking physicians to identify women to whom we can directly mail the questionnaires to eliminate the brochure step. All of this is subject to IRB approval however.

Key Research Accomplishments

- Produced literature review
- Designed theoretical models to guide research and analysis
- Completed and passed dissertation proposal
- IRB approval obtained
- Study materials prepared
- Developed relationships with key breast cancer surgeons in community
- Recruited first participant and collected data

Reportable Outcomes

- Passed dissertation proposal through faculty committee (proceeded to dissertation phase)
- Passed oral comprehensive examinations based on work on project

Conclusions

In conclusion, the first phase of the training project has been successfully completed. Ms. Shumay has passed her dissertation proposal through the committee and has proceeded to dissertation phase. Preliminary preparations are complete to carry out the research study, and recruitment of participants has actively begun. The award has supported a quality training experience for Ms. Shumay and has supported her advancing to the dissertation phase in her graduate training. In addition to supporting the quality training of a future breast cancer researcher, this project has the potential to further cancer research in a number of ways. This study should allow us to better understand the relationship between emotional distress and treatment decisionmaking in breast cancer, as well as to help underscore the importance of identifying and treating anxiety and depression after diagnosis. The results may serve to form the basis for further research in determining the appeal of CAM for emotionally distressed breast cancer patients with the goal of designing relevant interventions.

References

- Horowitz, M. M., Wilner, N. & Alvarez, W. (1979). Impact of event scale: A measure of subjective stress. *Psychosomatic Medicine*, 41, 209-218.
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Appendices

Dissertation Proposal:

**A Longitudinal Study of Emotional Distress and the Use of Complementary and
Alternative Medicine in Women with Breast Cancer**

Dianne M. Shumay, MA

Department of Psychology, Clinical Studies Program

Proposal Oral Defense Date: Tuesday May 14, 2002 10am

Defense Location: 102 Gartley Hall

Dissertation Committee:

Elaine M. Heiby, Chairperson

Anthony J. Marsella

Carolyn C. Gotay

Karl Minke

Gertraud Maskarinec

ABSTRACT

The latest studies exploring the use of complementary and alternative medicine (CAM) by breast cancer patients show high rates of use (39%-72%). Emotional distress, including depression and anxiety, is a common reaction to breast cancer diagnosis and treatment. Recently, several studies have found a connection between emotional distress and CAM use, including a survey we conducted of 1,168 Hawai'i cancer survivors, in which poorer emotional functioning was associated with the use of CAM. Previous studies of cancer patients implicate coping response as related both to patients' emotional distress and to their use of CAM. Additionally, studies of CAM use suggest that individuals with cancer possibly seek out CAM treatments to increase their sense of control over their disease, or because they perceive CAM to be of psychological benefit.

The purpose of this longitudinal study is to explore the relationship among emotional distress, coping response and CAM use in newly diagnosed breast cancer patients. The study has the following specific aims: (a) determine the extent to which levels of depression and anxiety and coping response at 3 months (T1) and 9 months (T2) post-diagnosis are related to degree of CAM use at T1 and T2; (b) determine whether CAM use at T1 predicts emotional distress at T2; and (c) identify the types of CAM used by women with higher levels of emotional distress.

Physicians will be contacted for permission to recruit patients. Our target sample size is 100 women. We expect participants to be representative of the population of Hawai'i, which includes a majority of individuals of Asian and Pacific Islander ancestry. Participants will be asked to complete a packet of questionnaires two times, at approximately 3 and 9 months post-diagnosis. The packet will include five instruments:

(a) the Center for Epidemiological Studies Depression Scale, (b) the State-Trait Anxiety Inventory, (c) the Mental Adjustment to Cancer Scale, (d) self-report items on CAM, and (e) self-report items on demographics and medical treatment for cancer. Emotional distress, coping, treatment and demographic variables will be explored as predictor variables for degree of CAM use using multiple regression.

The results may serve to form the basis for further research in determining the appeal of CAM for emotionally distressed breast cancer patients with the goal of designing relevant interventions.

Introduction

Breast cancer affects over 200,000 women annually in the U.S. and despite improvements in detection and treatment, it is a distressing, painful, disfiguring and often fatal disease (Jemal, Thomas, Murray, & Thun, 2002). When faced with a breast cancer diagnosis, many women experience mild to severe emotional distress including depression and anxiety (Epping-Jordan, et al., 1999). Although often declining in intensity, emotional distress also occurs later along the disease trajectory as women deal with the uncertainties and side effects of treatment, possible death, concerns about family (especially children), role uncertainty, post-surgical body image and sexual functioning, worries about cancer recurrence and other concerns (Payne, Sullivan, & Massie, 1996; Kornblith, 1998; Shapiro et al., 2001). The degree to which women experience emotional distress appears to be moderated by coping response. Women who take a passive, helpless/hopeless, fatalistic or pessimistic approach are more likely to experience depression or anxiety (Burgess, Morris, & Pettingale, 1988; Epping-Jordan et al.; Van't Spijker, Trijsburg, & Duivenvoorden, 1997). Emotional distress has emerged as a predictor of complementary and alternative medicine (CAM) use among women with breast cancer (Burstein, Gelber, Guadagnoli, & Weeks, 1999; Carlsson, Arman, Backman, & Hamrin, 2001). Active problem-focused coping (Sollner, et al., 2000) and anxious preoccupation (Carlsson, et al.) have also been related to CAM use by cancer patients. The purpose of this longitudinal study is to examine the relationship among socio-demographic and treatment variables, emotional distress, coping response and degree of CAM use in breast cancer patients at two time points, approximately three months and nine months post-diagnosis. This study will also explore the types of CAM

used by women with higher levels of anxiety and depression, as patients may use CAM for relief from the symptoms of emotional distress.

Emotional Distress

Emotional distress, including depression and anxiety, has long been understood as a common reaction to breast cancer diagnosis and treatment (Fallowfield, Hall, Maguire, & Baum, 1990; Hughes, 1982). Rates of prevalence of clinically significant depressive symptoms have been estimated at 31% in all cancer patients (Dugan, et al., 1998) and 34% in breast cancer cases (Epping-Jordan et al., 1999). Similarly, anxiety symptoms were present in 27% to 42% of breast cancer cases depending on time of assessment in a prospective study (Fallowfield et al.). In general, it appears that emotional distress is greater immediately after diagnosis and declines over the disease trajectory (Burstein et al., 1999; Cimprich, 1999; Grassi & Rosti, 1996; Poole, 1997). However, a meta-analysis of 58 studies found a significant decrease for anxiety but not depression over the course of the disease (Van't Spijker et al., 1997). In one study, 38% of breast cancer patients were depressed at a follow-up visit after chemotherapy had ended (Morasso et al., 2001). Women with poorer emotional functioning pre or post diagnosis with breast cancer continued to exhibit poorer functioning when assessed later on in the course of their disease (Ell, Nishimoto, Morvay, Mantell, & Hamovitch, 1989; Maunsell, Brisson, & Deschenes, 1992).

Younger women, and individuals with more severe breast cancer, more physical limitations and more symptoms, including lymphedema, were more likely to experience emotional distress (Badger, Braden, & Mishel, 2001; Epping-Jordan, et al., 1999; Passik & McDonald, 1998; Van't Spijker et al., 1997; Vinokur, Threath, Caplan, & Zimmerman,

1989; Walker, Kohler, Heys, & Eremin, 1998). In addition, women with breast cancer were more likely to experience emotional distress when they exhibited a passive, helpless/hopeless, fatalistic or pessimistic coping style (Burgess et al., 1988; Epping-Jordan, et al.; Van't Spijker et al.).

Coping Response

Greer and Watson (Greer, Morris, & Pettingale, 1979; Watson, Greer, Blake, & Shrapnell, 1984) originally described the coping styles exhibited by cancer patients (denial, fighting spirit, stoic acceptance, helplessness/hopelessness) that led to the formation of the Mental Adjustment to Cancer Scale (MAC) and its subscales: helplessness/hopelessness, fighting spirit, fatalism and anxious preoccupation. (Watson et al., 1988; Watson, Haviland, Greer, Davidson, & Bliss, 1999). *Helplessness/hopelessness* is the response to cancer characterized by pessimism and giving up. *Fighting spirit*, on the other hand, is the response that cancer patients have when they accept their diagnosis but remain optimistic and vow to fight the disease. *Fatalism or stoic acceptance* is the response by patients in which they fully accept the reality of their cancer but with resignation and a sense of futility. And finally, *anxious preoccupation* is characterized by a constant vigilance with bodily symptoms and fears about cancer spread and recurrence.

MAC coping response style has been shown to be related to degree of emotional distress in breast cancer and other cancer patients. Fighting spirit predicted better psychological functioning, and helplessness/hopelessness predicted worse psychological functioning across studies (Akechi et al., 1998; Grassi & Rosti, 1996; Lampic et al., 1994; Sherliker & Steptoe, 2000; Van't Spijker et al., 1997; Watson et al., 1991). Fatalism also predicted worse emotional functioning (Grassi & Rosti; Lampic et al.; Van't

Spijker et al.; Watson et al.). Lastly, anxious preoccupation was positively correlated with psychological wellbeing in patients with advanced cancer (Sherliker & Steptoe), but it was predictive of worse psychological functioning in other studies (Grassi & Rosti; Lampic et al.; Van't Spijker et al.; Watson et al.).

Complementary and Alternative Medicine

The National Institutes of Health National Center for Complementary and Alternative Medicine (NCCAM) defines CAM as “those healthcare and medical practices that are not currently an integral part of conventional medicine” (NCCAM, 2002). To further define CAM and set a standard for classification for the many individual types of CAM therapies, NCCAM has designated a list of 5 domains of CAM: (1) alternate medical systems, (2) mind-body interventions, (3) biologically-based treatments, (4) manipulative and body-based methods, and (5) energy therapies (NCCAM, 2002). Cancer patients in Hawaii use a variety of CAM treatments, the most popular of which include herbs and supplements, vitamins and minerals, religious/spiritual healing, special diets, meditation techniques, massage, guided imagery, support groups, acupuncture, healing touch, yoga, naturopathy, Native Hawaiian healing, and homeopathy (Gotay, Hara, Issell, & Maskarinec, 1999; Maskarinec, Shumay, Kakai, & Gotay, 2000; Shumay, Maskarinec, Gotay, Kakai, & Heiby, 2002).

CAM use is popular among breast cancer patients. The latest studies show high rates of use, ranging from 39% (Burstein et al., 1999) to 84% (Morris, Johnson, Homer, & Walts, 2000). Prevalence rates within this range have also been reported for CAM use by breast cancer patients in Hawaii. Gotay and colleagues (1999) in a study of 367 cancer patients in Hawai'i (the majority of whom were of Asian and Pacific Islander origin)

found that overall 36% of participants reported CAM use, with 42% of breast cancer patients reporting use. In a recent study we conducted in Hawaii with 1,168 cancer survivors, 39% of the breast cancer survivors ($n=313$) reported CAM use after cancer diagnosis, compared to 25% for all types of cancer (Maskarinec et al., 2000). Factors predicting CAM use in women with breast cancer include: younger age, use of CAM before diagnosis, higher education, support group attendance and Caucasian ethnicity (Adler, 1999; Boon et al., 2000; Crocetti et al., 1998; Lee, Lin, Wrench, Adler, & Eisenberg, 2000; Rees et al., 2000). Most cancer patients who use CAM do so in conjunction with conventional biomedical treatment (Cassileth, Lusk, Strouse, & Bodenheimer, 1984; Lerner & Kennedy, 1992; Sollner et al., 2000).

Several studies have found an association between emotional distress and CAM use in community and general cancer samples. In a large national telephone survey ($n=9,585$), the use of CAM was significantly related to anxiety and depressive disorders (Unutzer et al., 2000). In a study of cancer patients, greater anxiety but not depression was associated with CAM use (Downer et al., 1994). Among Hawaii cancer survivors, significantly poorer emotional functioning on a quality of life scale was related to CAM use (Maskarinec et al., 2000). In contrast, in a survey of cancer patients, pain patients and a community sample, positive affect and hypnotizability were correlated with the number of CAMs used, while negative affect was not correlated with CAM use (Owens, Taylor, & Degood, 1999). A study of German cancer patients undergoing radiation also failed to find a relationship between emotional distress and CAM use. CAM use was better predicted by active coping behavior, such as information-seeking and problem-solving.

However, the authors excluded types of CAM that could be considered psychological therapies, such as relaxation and self-help groups (Sollner et al., 2000).

Among breast cancer patients, CAM users reported using CAM for psychological support (Crocetti et al., 1998; Gotay et al., 1999), and having received psychological counseling was a strong predictor of CAM use (Lee et al., 2000). Furthermore, in a longitudinal study of women with breast cancer, investigators found elevated scores on a measure of psychological distress to be strongly related to the adoption of CAM use after diagnosis (Burstein et al., 1999). Recently, in a cohort study comparing 60 Swedish women who entered a complementary medicine clinic with 60 matched controls who used only conventional treatment for breast cancer, the CAM group was more likely to report lower quality of life, including poorer emotional functioning. This group also tended to exhibit an anxious preoccupation coping style (Carlsson et al., 2001). In a study of Austrian breast cancer patients, the women who had an active problem-oriented coping style were more likely to be CAM users, while a subgroup of heavy CAM users reported worse emotional functioning and more depressive coping styles than light users or nonusers of CAM (Moschen et al., 2001).

A number of studies have reported that cancer patients perceive CAM to be of psychological benefit. In one study, 63% of cancer patients who used CAM experienced psychological benefits, such as increased sense of control, reduction in anxiety and improved coping with their illness (Miller et al., 1998). In a study with cancer patients and pain patients, greater improvement in psychological well-being was associated with the number of CAM therapies used (Owens et al., 1999). Cancer patients, including those with breast cancer, have stated that they seek out CAM because they expect

psychological benefit (i.e., as a source of hope, to increase sense of control, to reduce stress, to strengthen psychological resources for healing and coping with cancer and to improve quality of life; Gotay et al., 1999; Salmenpera, Suominen, Lauri, & Puukka, 2001; Weis et al., 1998; Yates et al., 1993).

The decision-making process leading to CAM use by women with breast cancer appears to vary across the disease trajectory (Gotay & Bultz, 1986). Truant & Bottorff (1999) in a qualitative analysis of the responses of 16 women with breast cancer, describe three phases of CAM decisionmaking: (1) getting something in place -- in the face of a diagnosis, women quickly choose one or more types of CAM; (2) hand-picking CAM -- after the initial sense of urgency, women have the chance to more carefully select the CAM that suits them and; (3) fine-tuning regimen for maintenance -- women choose new CAMs, continue some CAMs from before, and drop others in an effort to select the best combination for longer term needs.

Purpose and Hypothesis

This study will examine the extent to which levels of depression and anxiety and coping response at three months (T1) and nine months (T2) post-diagnosis are related to CAM use at T1 and T2. The model for this analysis is loosely based on Andersen's healthcare utilization model in which predisposing, maintaining and enabling factors are theorized to predict the use of health services (Andersen, 1995; Andersen & Newman, 1973). Figure 1 depicts a model in which three categories of variables are expected to predict greater degree of CAM use among women with breast cancer. First, greater emotional distress, defined as greater levels of depression and anxiety, will be related to more CAM use. Next, the coping response styles anxious preoccupation and fighting

spirit are expected to have a positive effect on CAM use, while fatalism and helplessness/hopelessness would be expected to have a negative effect. Lastly, a number of socio-demographic and clinical variables are also expected to predict greater CAM use: younger age, higher income, higher education level, being married, Caucasian ethnicity and receiving chemotherapy.

Figure 2 depicts a more complex model in which the variable categories are shown to be inter-related. This model is based upon Kornblith's (1998) vulnerability model of psychosocial adaptation of cancer survivors with the addition of CAM use as an outcome as well as a mediating variable. In this model, breast cancer and treatment are seen as the precipitating events that ultimately lead to psychosocial adaptation and CAM use. Sociodemographic and coping responses are viewed as mediating variables in that they represent the presence or absence of resources that lead to better or worse adaptation. The longitudinal nature of this study allows us to explore hypothesized temporal relationships between the variables. First, greater emotional distress at T1 is expected to predict greater degree of CAM use at T2, in so much as patients would be expected to use CAM in response to depression or anxiety; while greater degree of CAM use at T1 is expected to predict less emotional distress at T2 due to the possible psychological benefits of using CAM.

We also expect that the types of CAM sought after by women with higher levels of anxiety and depression will be those that are categorized in the Mind-Body domain as defined by NCCAM (2002). Additional aims of the study are to provide pilot data for further research in developing interventions (such as mood regulation skills, coping skills

training or treatment information) to meet the emotional needs and healthcare expectations of breast cancer patients.

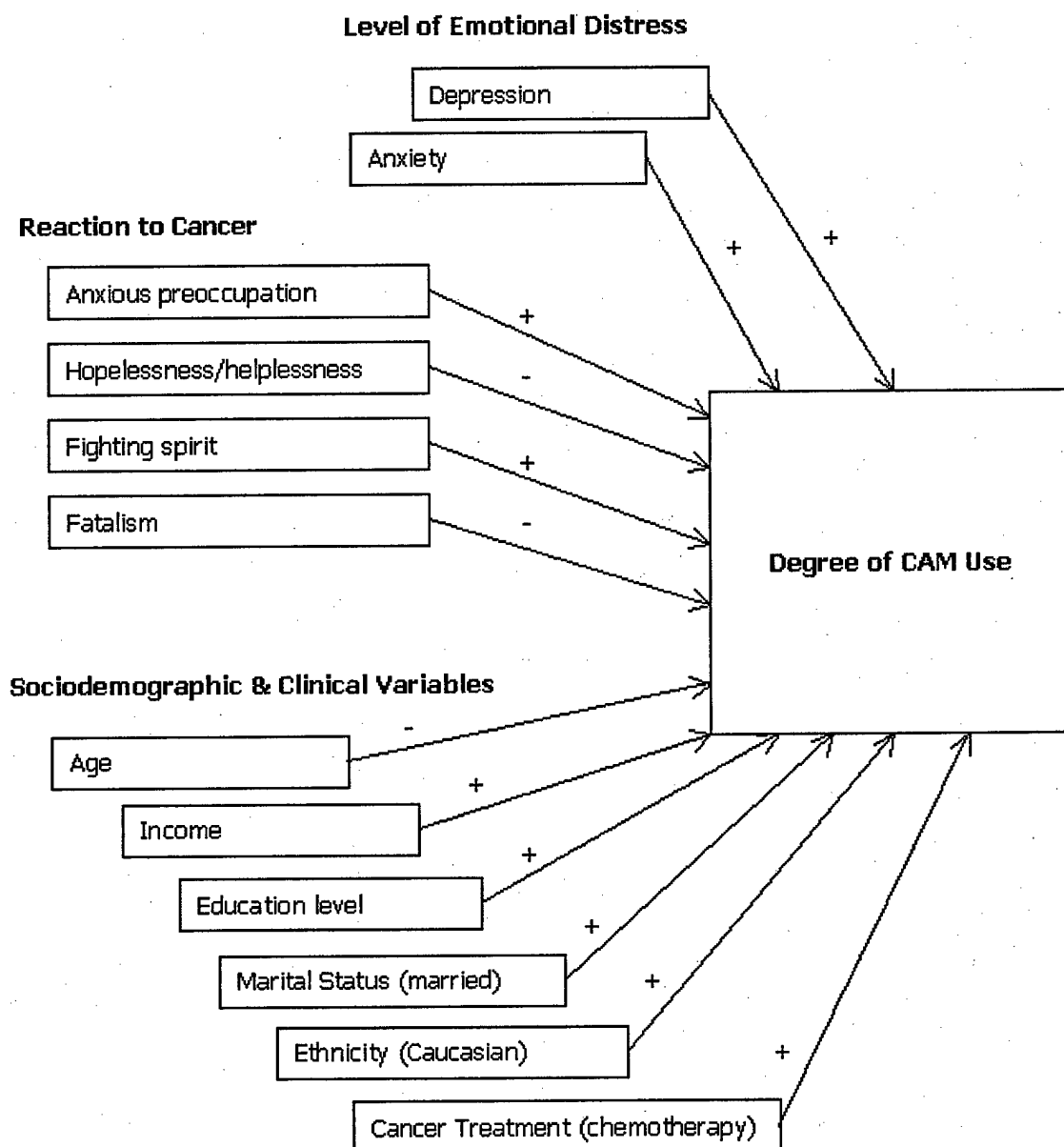


Figure 1. Hypothetical model of determinants of degree of CAM use by women with breast cancer.

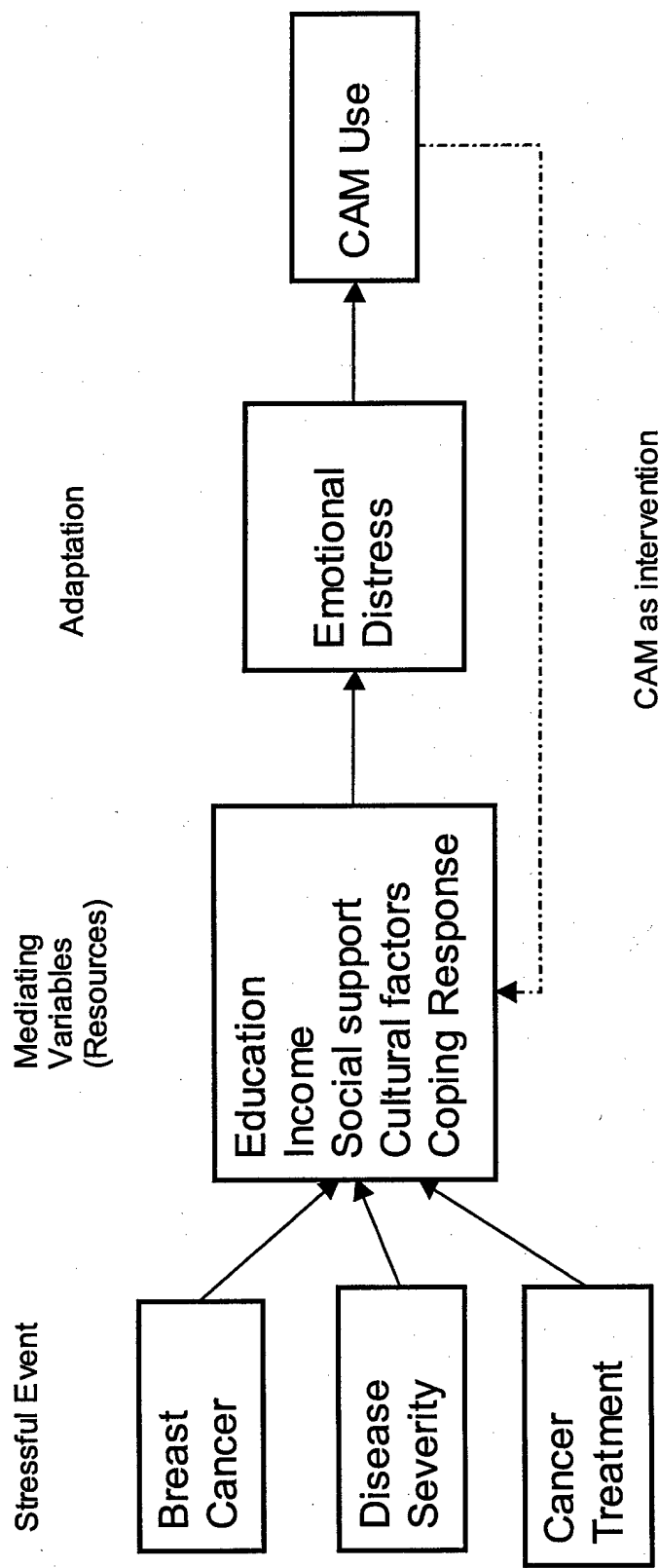


Figure 2. Vulnerability model of psychosocial adaptation with CAM utilization (Adapted from Kornblith, 1998)

METHOD

Recruitment of Participants

We will attempt to recruit 125 women newly diagnosed with breast cancer by referral from surgeons and clinics treating breast cancer cases. Inclusion criteria include: female residents of Hawai'i, over 18, newly diagnosed with biopsy-confirmed in situ or invasive breast cancer, and no prior diagnosis of any cancer. Women will be excluded from the study if their physician withdraws permission for their participation.

In order to estimate the expected population of newly diagnosed women in Hawaii, we used the most recent numbers available from the Hawaii Tumor Registry (HTR). According to the HTR in 1999, 1,138 women were diagnosed with in situ or invasive breast cancer in Hawai'i. Some 993 of these cases were those in which this was the first diagnosis of any cancer and were not staged as distant metastasis. Approximately half (496) of these were diagnosed in Oahu's major hospitals (the source of expected referrals). Of approximately 496 women, we might expect about ten percent to be eliminated from participation by their attending physicians or to be excluded for other reasons. Of the remaining number, expecting a 50% response rate and a 25% attrition rate, we are targeting 125 women to begin and 100 women to complete the study. The 50% response rate estimate is based on a recent study using mailed questionnaires, in which 56% of eligible breast cancer patients participated (Maskarinec et al., 2000).

Given our previous survey, it is likely that approximately 30% of respondents will report the use of some type of CAM (Maskarinec et al., 2000). Data from the 1999 HTR suggest the following ethnic backgrounds for breast cancer patients: 35% Japanese, 27% Caucasian, 14% Native Hawaiian, 10% Filipino, 7% Chinese, and 7% from other ethnic

groups. Cancer stage represented by the 1999 HTR data shows of the 1,138 breast cancer cases, 21% were *in situ*, 57% local, 18% regional and 4% distant or unknown.

Sources of Data

Questionnaires (Appendix A):

- 1) The Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) is a widely used 20-item instrument for measuring depressive symptoms in the general clinical population. Respondents rate the frequency of a particular thought or behavior occurring over the past week from a four-option Likert-type scale ranging from "rarely" to "most of the time." A psychometric analysis with a sample of breast cancer patients found the instrument to perform with excellent reliability (internal consistency: coefficient alpha >0.85) and demonstrated construct validity (Hann, Winter, & Jacobsen, 1999). Across clinical populations, the scale correlated well with criterion validity measures including clinical interviews and was sufficiently sensitive to detect changes in depressive symptoms over time (Weissman, Sholomskas, Pottenger, Prusoff, & Locke, 1977).
- 2) State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, & Lushene, 1970) is a well-validated scale measuring both the more stable trait anxiety as well as variations in anxiety states and is thus useful for repeated measures analysis. The instrument has been used in thousands of studies across many clinical populations including studies of psychosocial aspects of breast cancer (e.g. Fallowfield et al., 1990).
- 3) The Mental Adjustment to Cancer Scale (MAC; Watson et al., 1999) is a 40-item instrument designed to measure adjustment and coping style with four subscales: Fighting Spirit; Anxious Preoccupation, Fatalism, and Helplessness/Hopelessness.

The instrument received construct validity support and showed moderate to high internal consistency across the four subscales (Cronbach's $\alpha = 0.64 - 0.85$) in a study with breast cancer patients (Osborne, Elsworth, Kissane, Burke, & Hopper, 1999).

- 4) Health Therapies Questionnaire is a two-page questionnaire to assess CAM use designed for this study. A psychometrically-sound CAM self-report questionnaire has not yet been developed. For this study, we began with the self-report items on CAM use including a checklist of 22 CAM types from the questionnaire we used in our previous study (Maskarinec et al., 2000) as well as questionnaires used by others in studying CAM with cancer patients (e.g. Gotay et al., 1999; Miller et al., 1998). We further adapted the list from a content analysis of cancer patient interviews in which participants described the types of CAM they used (Shumay et al., 2002). We also amended the response options to include a Likert-type scale to rate the degree to which respondents regularly engage in the therapy. This is intended to provide an additional dimension of the degree of CAM use as suggested by Shumay et al. (2002).
- 5) Background and Treatment History Questionnaire, a two-page questionnaire designed for this study containing self report items gathering information about participants' demographics and medical treatments for cancer.

Procedure

To identify women newly diagnosed with breast cancer, we will contact local hospitals (Kaiser-Permanente and Kapiolani), as well as Oahu-based surgeons with high volume breast cancer practices. Women referred through these means will either: (a) be sent a letter inviting participation, (b) receive a brochure from their physician's office advertising the study, or (c) be recruited in person at their clinic or physician's office by a

member of the study team. Interested women will be asked to complete a reply card with contact information and return it to the study team by mail or through the physician's office. All women contacted will have the approval of their physician for participation in the study.

Eligible women who have responded by returning a reply card will be contacted by the research team to set up a meeting between the principal investigator and the potential participant to provide information about the study and obtain consent. The meeting will take place at the physician's office, the Cancer Research Center or another location convenient to the participant. The participant will sign the consent form in the presence of a witness and will be given a copy of the consent form and asked to complete the packet of questionnaires. The questionnaire will take approximately 30-45 minutes to complete. Participants will be sent a second packet of questionnaires at 9 months post diagnosis. Participants who do not respond to the mailing will be telephoned and sent up to two reminder postcards. To preserve anonymity, two separate databases will be kept for participants, one containing names and contact information, and the other containing only study ID numbers and study data.

Proposed Analysis

Participants and nonresponders will be compared along available demographic and disease characteristic variables using chi-square analysis to examine degree of selection bias. CAM types will be categorized by NCCAM domain according to the definition (NCCAM 2002). Descriptive statistics will summarize results from T1 and T2 for the participants' age, ethnicity, marital status, income, occupation, education level, stage at diagnosis, biomedical cancer treatments received, biomedical cancer treatments

refused, type of CAM used, number of CAMs used, NCCAM category, regularity of CAM use, scores on the STAI, CES-D, and MAC subscales. Psychological (i.e. depression, anxiety, and coping), treatment and demographic variables at T1 and T2 will be explored as predictor variables for degree of CAM use at T1 and T2 using multiple regression. Degree of CAM use at T1 will also be explored as a predictor for depression and anxiety at T2. To determine the association between emotional distress and type of CAM, CAM types will be divided into *body* therapies (herbs, vitamins, diet, acupuncture, and other therapies that act on or with the body) and *mind* therapies (relaxation, meditation, guided imagery, spirituality and other therapies that involve psychological or mental processes). Additional exploratory analyses will be undertaken given sufficient data.

Where multiple analyses of mean scores are calculated, we will use the Bonferroni adjustment. Given our proposed recruitment techniques, the sample surveyed may not be representative of all women diagnosed with breast cancer in Hawaii. Only women from high volume Honolulu surgical oncology practices who are approved by their doctors will be asked to volunteer. We will make every effort to prevent participant attrition by following up with nonresponders via mail and by telephone. For those participants who do not complete the second set of questionnaires, we will eliminate them from the analysis.

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APPENDIX A

**BREAST CANCER, EMOTIONAL WELLBEING AND
COMPLEMENTARY AND ALTERNATIVE MEDICINE STUDY**

QUESTIONNAIRE PACKET

CANCER RESEARCH CENTER OF HAWAII
University of Hawaii at Manoa

Principal Investigator: Dianne M. Shumay, MA

564-5840

Co-Investigator: Gertraud Maskarinec, MD PhD

586-3078

CES-D

Fill in the circle for each statement which best describes how often you felt or behaved this way
 -- DURING THE PAST WEEK.

	Rarely or None of the Time (Less than 1 day)	Some or Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 Days)	Most or all of the Time (5-7 days)
I was bothered by things that usually don't bother me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not feel like eating: my appetite was poor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I could not shake off the blues even with help from my family or friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was just as good as other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had trouble keeping my mind on what I was doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that everything I did was an effort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt hopeful about the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought my life had been a failure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt fearful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My sleep was restless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was happy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I talked less than usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt lonely	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People were unfriendly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I enjoyed life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had crying spells	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that people disliked me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I could not get "going"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

MAC SCALE

A number of statements are given below which describe people's reactions to having cancer. Please fill in the circle underneath the statement, indicating how far it applies to you at present. For example, if the statement definitely does not apply to you then you should fill in the circle in the first column.

	Definitely does <u>not</u> apply to me	Does <u>not</u> apply to me	Applies to me	Definitely applies to me
I have been doing things that I believe will improve my health e.g. changed my diet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I can't do anything to cheer myself up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that problems with my health prevent me from planning ahead	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe that my positive attitude will benefit my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't dwell on my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I firmly believe that I will get better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that nothing I can do will make a difference	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've left it all to my doctors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that life is hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have been doing things that I believe will improve my health, eg. Exercised	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Since my cancer diagnosis I now realize how precious life is and I'm making the most of it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've put myself in the hands of God	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have plans for the future, e.g. holiday, jobs, housing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about the cancer returning or getting worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've had a good life what's left is a bonus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think my state of mind can make a lot of difference to my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that there is nothing I can do to help myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I try to carry on my life as I've always done	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would like to make contact with others in the same boat	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am determined to put it all behind me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty in believing that this happened to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I suffer great anxiety about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am not very hopeful about the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
At the moment I take one day at a time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel like giving up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to keep a sense of humor about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other people worry about me more than I do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think of other people who are worse off	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am trying to get as much information as I can about cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that I can't control what is happening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to have a very positive attitude	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I keep quite busy, so I don't have time to think about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I avoid finding out more about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I see my illness as a challenge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel fatalistic about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel completely at a loss about what to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel very angry about what has happened to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't really believe I had cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I count my blessings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to fight the illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

HEALTH THERAPIES QUESTIONNAIRE

Below is a list of therapies that some people use for health reasons, please indicate which therapies, if any that you have tried. Please circle the appropriate answer for each therapy.

	Have you ever used this?	Do you currently use this	Did you start using this before or after cancer diagnosis?	How regularly do you use this?
Chiropractic	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Acupuncture/ Acupressure	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Massage therapy/bodywork	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Homeopathic medicine	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Relaxation techniques	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Hypnosis or self- hypnosis	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Yoga	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Religious healing or prayer	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Support group	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Osteopathy	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Traditional Hawaiian healing	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Energy healing (eg., Healing touch, Reiki)	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Meditation	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Guided Imagery/Visualization	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Naturopath	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY
Tai Chi or Chi Gong	Y N	Y N	BEFORE AFTER	1 2 3 4 5 6 7 NEVER VERY REGULARLY

Aromatherapy	Y	Y	BEFORE	1 2 3 4 5 6 7
	N	N	AFTER	NEVER VERY REGULARLY
Herbal/Botanical Treatment	Y	Y	BEFORE	1 2 3 4 5 6 7
	N	N	AFTER	NEVER VERY REGULARLY
Special Diet	Y	Y	BEFORE	1 2 3 4 5 6 7
	N	N	AFTER	NEVER VERY REGULARLY
Vitamins	Y	Y	BEFORE	1 2 3 4 5 6 7
	N	N	AFTER	NEVER VERY REGULARLY
Other Supplements	Y	Y	BEFORE	1 2 3 4 5 6 7
	N	N	AFTER	NEVER VERY REGULARLY
Exercise	Y	Y	BEFORE	1 2 3 4 5 6 7
	N	N	AFTER	NEVER VERY REGULARLY
Other non-medical therapy	Y	Y	BEFORE	1 2 3 4 5 6 7
	N	N	AFTER	NEVER VERY REGULARLY

Please list herbal/botanical therapies you take currently _____

Please list vitamins, minerals and other supplements you take currently _____

Please describe any special diets that you are currently on _____

Please list any other non-medical therapy you have used that is not included on the list above _____

Is there any non-medical therapy that you would like your regular medical provider to offer? Which ones? _____

If your healthcare team offered psychological counseling to help you and your family cope with cancer, would you choose to receive it? Why or why not? _____

Background and Treatment History Questionnaire

1) Your Date of Birth _____

4) Please list your occupation (if retired, list previous occupation)

2) What best describes your ethnicity?

- ☐ Japanese
- ☐ Caucasian
- ☐ Chinese
- ☐ Filipino
- ☐ Native Hawaiian
- ☐ Other (Specify below): _____

Alphabetize

5) What is your family's annual income?

~~(optional)~~

- ☐ <\$15,000
- ☐ \$15,000-\$25,000
- ☐ \$25,000-\$50,000
- ☐ \$50,000-\$100,000
- ☐ >\$100,000

3) What is the highest level of education that you have reached?

- ☐ Some high school
- ☐ HS diploma or GED
- ☐ Some college or trade school
- ☐ Some graduate school
- ☐ Graduate or prof degree

6) What is your current marital status

- ☐ Single
- ☐ Co-habiting
- ☐ Married
- ☐ Divorced
- ☐ Widowed

7) Which treatments have you received for breast cancer? (Select all that apply)

- ☐ Mastectomy
- ☐ Mastectomy with sampling of the lymph nodes
- ☐ Mastectomy and reconstruction at the same time
- ☐ Lumpectomy (partial mastectomy) with sampling of lymph nodes under arm
- ☐ Lumpectomy (partial mastectomy) without sampling of lymph nodes under arm
- ☐ Chemotherapy
- ☐ Radiation
- ☐ Hormonal therapy (e.g. Tamoxifen)
- ☐ Breast reconstruction after initial surgery
- ☐ Prophylactic surgery (removal of non-cancerous breast to reduce future breast cancer risk)
- ☐ None of these

8) What stage was the breast cancer?

- ☐ Stage 1
- ☐ Stage 2
- ☐ Stage 3
- ☐ Stage 4
- ☐ Don't know

9) How big was the tumor? _____

10) Was the tumor *in situ*?

- ☐ Yes
☐ No
☐ Don't know

11) Was the cancer found in your lymph nodes?

- ☐ Yes
☐ No
☐ Don't know

12) Was the cancer metastasized (i.e. spread to other parts of the body)

- ☐ Yes
☐ No
☐ Don't know

13) Are there any medical treatments that your doctor recommended you receive that you chose not to take?

- ☐ YES
☐ NO

14) If yes to question 13, please list the treatments you chose not to undergo and give reasons for your decision.
